



# **Developmental Disabilities Surveillance: Methods and Results from the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)**

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# What are Developmental Disabilities?

- **Group of severe chronic conditions manifested during developmental period**
- **Attributable to an impairment in physical, cognitive, speech or language, psychological, or self-care areas**
- **In the US, 17% of children <18 years of age were reported to ever have had a DD,**
  - ◆ **Ranging from 0.2% for cerebral palsy to 6.5% for learning disabilities.**



# Public Health Importance

- **Developmental disabilities have a substantial impact on health and educational functioning of affected children compared to their nonaffected counterparts:**
  - **Twice as many school-days lost**
  - **2.5 fold increase likelihood of repeating a grade**
  - **1.5 times more doctors visits**
  - **3.5 times more hospital stays**

\*Source: Boyle CA, et al. Prevalence and health impact of developmental disabilities in US children. Pediatrics. 1994; 93:399-403.



# Public Health Importance

## Cost of Developmental Disabilities

- **State and Federal education departments spend about \$36 billion each year on special education programs for individuals, 3-21 years of age, with developmental disabilities.\***

**\*Source: U.S. Department of Education. 1997. To Assure the Free Appropriate Public Education of All Children with Disabilities. Nineteenth Annual Report to Congress on the Implementation of The Individuals with Disabilities Education Act.**

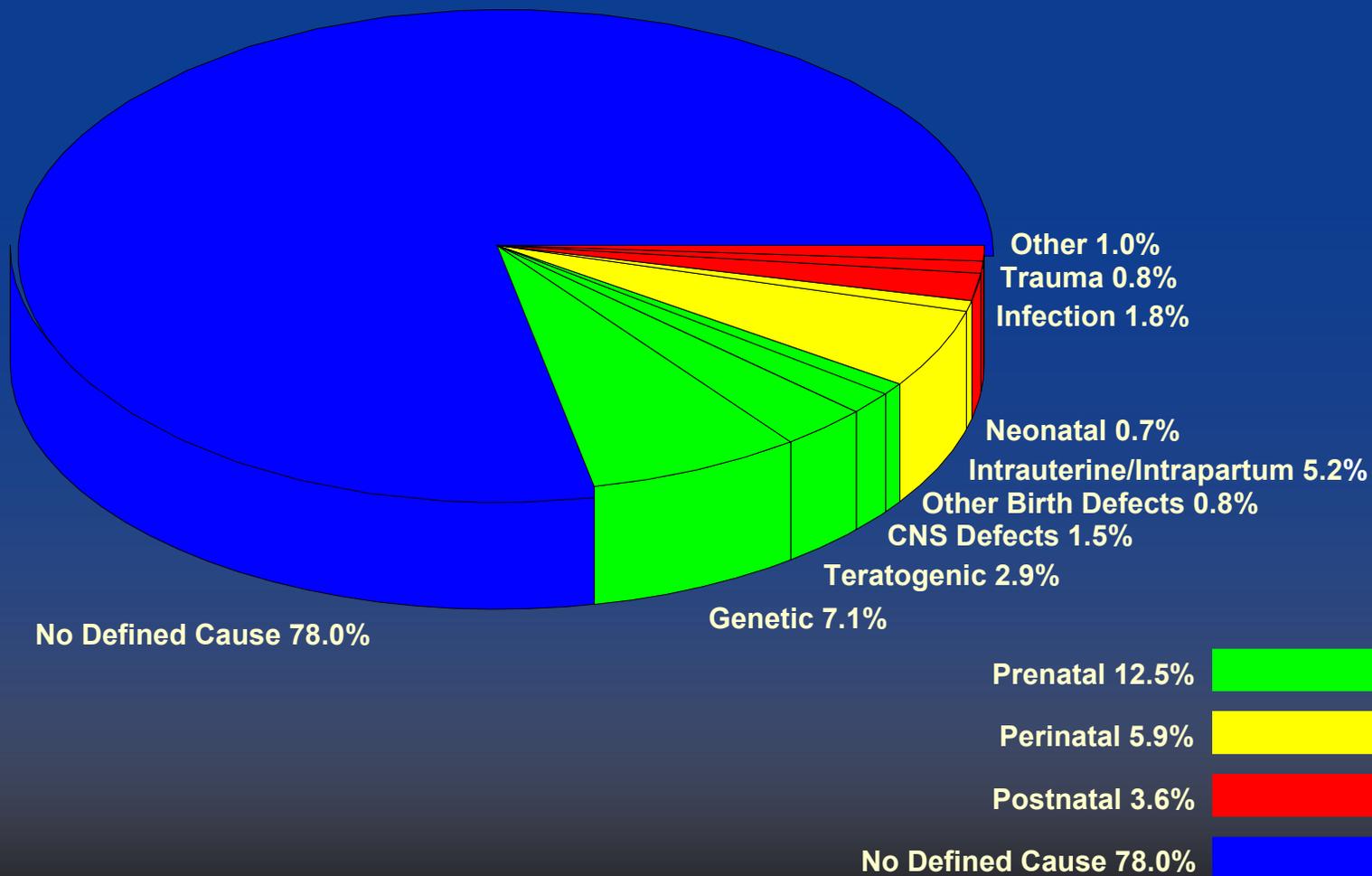


# Understanding the Epidemiology of Developmental Disabilities

- While varying by type and severity, for a large proportion of developmental disabilities the etiology is unknown.
- Epidemiology is a science to better understand etiology on a population-basis; surveillance is the first step in this process, yet conducting surveillance of developmental disabilities is challenging.



# Possible Causes for Mental Retardation: 10-Year-Old Children in Metropolitan Atlanta, 1985-1987





# **Ongoing Surveillance of Developmental Disabilities:**

## **Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)**



## **MADDSP Objectives**

- **To provide regular and systematic monitoring of prevalence rates of selected developmental disabilities according to various demographic characteristics of the children and their mothers**
- **To provide a framework for special studies of children who have select developmental disabilities by establishing a population-based case series of such children.**



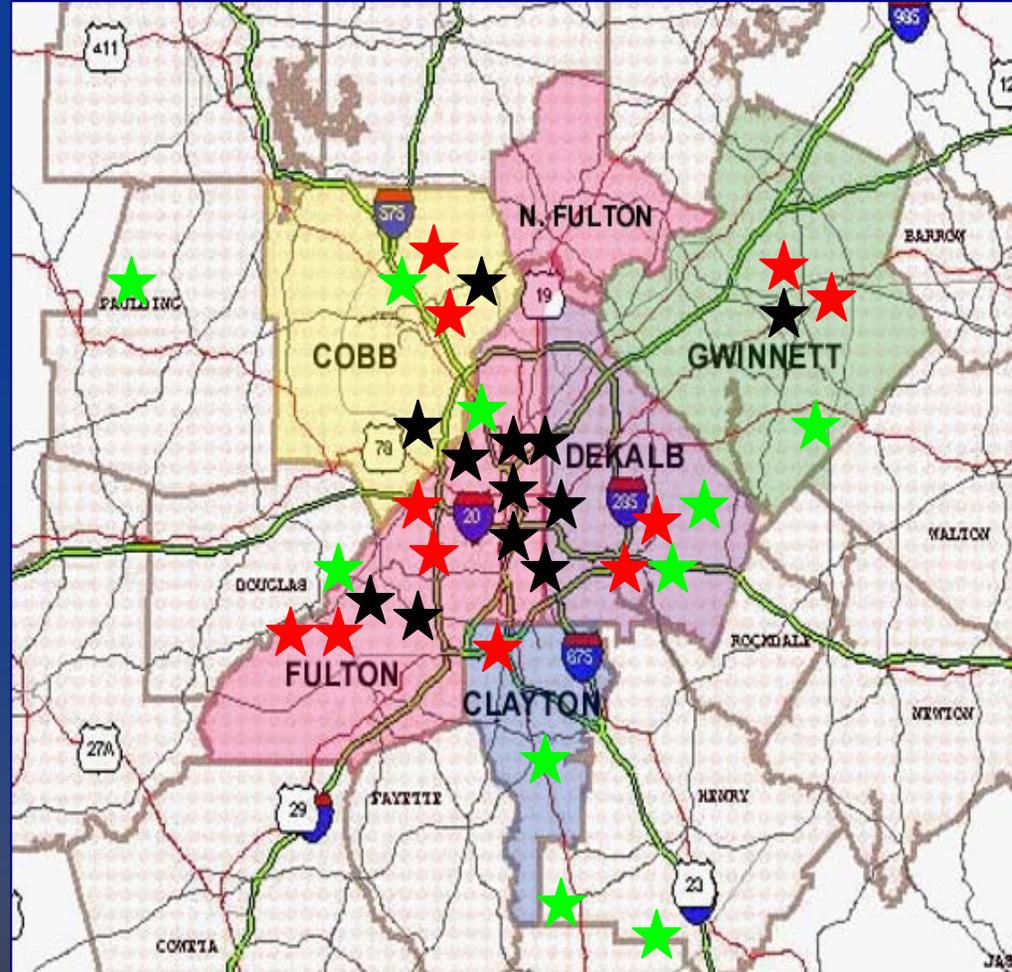
# **Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)**

- **MADDSP ongoing since 1991**
- **Population-based**
- **Five counties in metro Atlanta**
- **Children aged 3-10 years, 1991-1994 including:  
Mental retardation, Cerebral palsy, Hearing loss, and  
Vision impairment,**
- **Autism was added in 1996,**
- **MADDSP will focus on 8 year olds in future**
- **Record review from multiple sources with schools as  
the primary source**



# MADDSP Data Sources

- ★ **GA Department of Education (DOE)**
  - Metro Atlanta school systems – special education
  - State schools
  - Regional psychoeducational programs
- ★ **GA Department of Human Resources (DHR)**
  - Division of Public Health/CMS
  - Division of MR/MH/SA
- ★ **Hospitals, clinics, other private medical sources**





## **MADDSP: Access to Records**

- **Goal: to get as complete a count as possible of all children with select DD living in the study area during the period of interest.**
- **Institutional or agency permission to review records without parental consent is the best way to accomplish this goal.**



## **MADDSP: Access to Records**

- **MADDSP is approved by the CDC Institutional Review Board.**
- **MADDSP is considered public health surveillance**
  - ◆ **Parental consent not required to access records**
  - ◆ **Institutional permission to access records required from each data source.**
  - ◆ **School sources: Memorandum of Understanding (MOU)**
  - ◆ **Non-school sources: Individual agency permission**

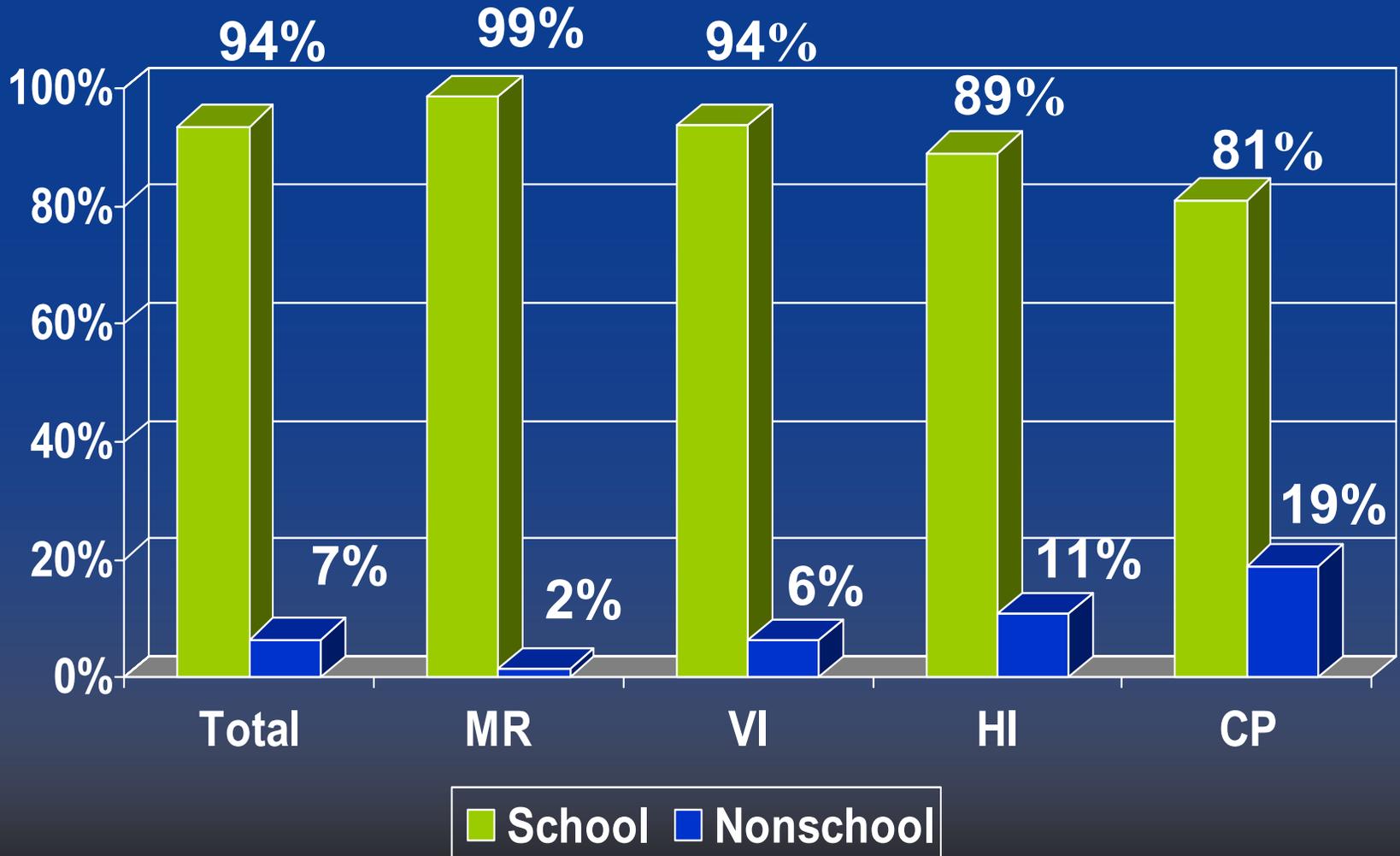


# MADDSP: Assurance of Confidentiality

- **MADDSP has obtained Assurance of Confidentiality under Section 308 (d) of the Public Health Service Act**
  - ◆ **Allows additional protection not currently provided by the Privacy Act or the Freedom of Information Act**
    - ★ **Sensitive information can be collected without possible dangers of release of information**
    - ★ **Not liable to public access**



# 1994 MADDSP Data Sources: Importance of School Sources





# MADDSP: Types of Data Collected

## Demographic:

- ◆ Child and mother identifying information
- ◆ Date of birth, race, sex

## Educational:

- ◆ Primary exceptionality, developmental/psychometric tests

## Medical/Clinical:

- ◆ Physical findings
- ◆ Associated medical conditions
- ◆ Other developmental disabilities



# MADDSP Surveillance Case Definitions

## Mental Retardation (MR)

I.Q.  $\leq$  70 on most recently administered psychometric test.

## Cerebral Palsy (CP)

A diagnosis of CP made by a qualified health professional (or) a description of physical findings consistent with CP. Final case determination is made by the program's developmental pediatrician.

## Hearing Loss (HL)

Measured bilateral pure tone hearing loss averaging 40 decibels or higher (unaided) in the better ear

## Vision Impairment (VI)

Measured visual acuity of 20/70 or worse in the better eye with correction



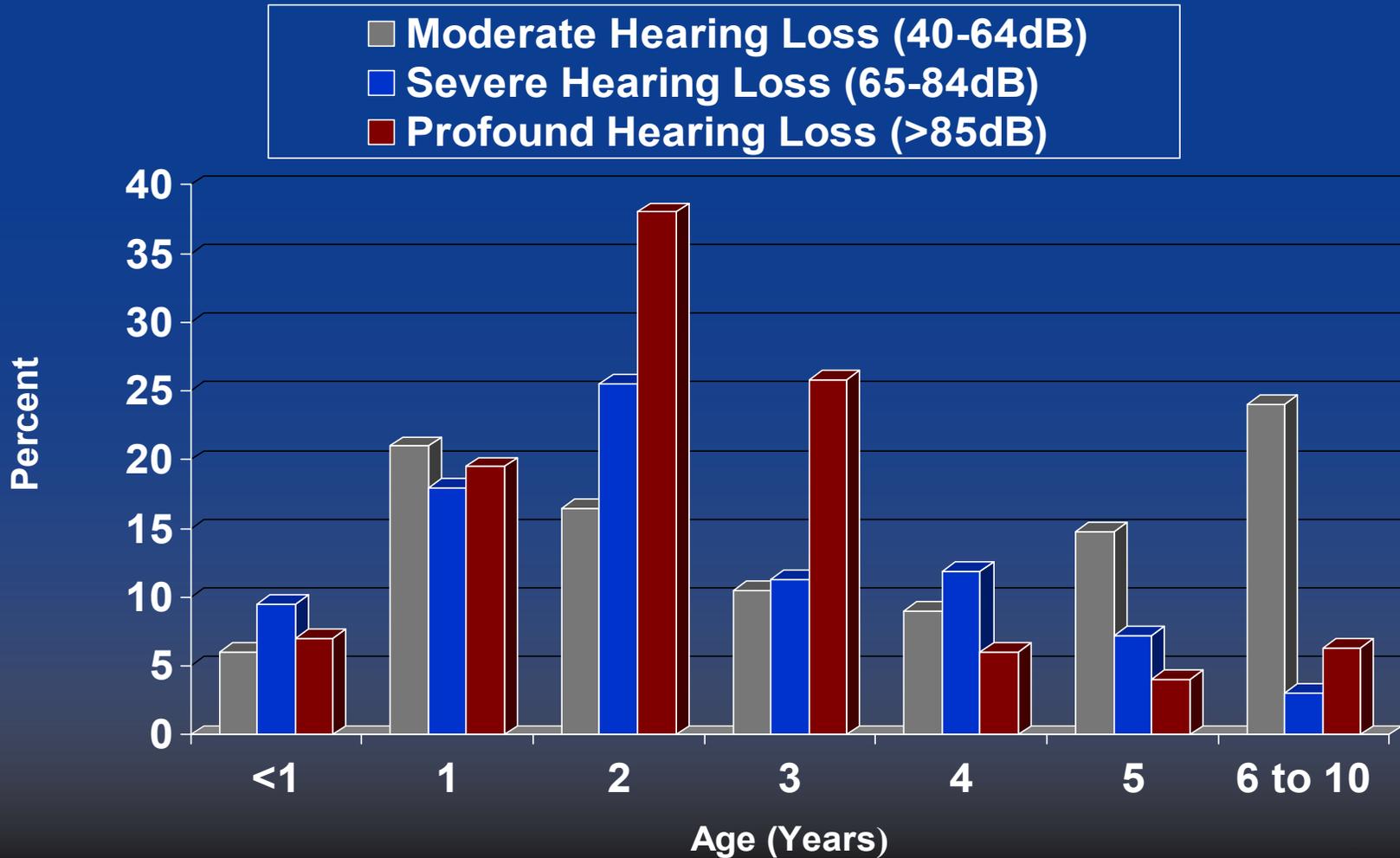
# Prevalence of Developmental Disabilities Among Children in MADDSP 3-10 Years of Age (1991-1994)

	<u>Number of Children</u>	<u>Rate per 1,000 Children</u>
<b>Mental Retardation:</b>	<b>4,625</b>	<b>9.7</b>
<b>Cerebral Palsy:</b>	<b>1,207</b>	<b>2.8</b>
<b>Vision Impairment :</b>	<b>395</b>	<b>0.9</b>
<b>Hearing Loss:</b>	<b>477</b>	<b>1.1</b>

- **Children with multiple disabilities: 842 (15%)**



# Percentage of Children with Presumed Congenital Sensorineural Hearing Loss, by Earliest Known Age at Diagnosis and Hearing Level





# MADDSP Linkages

## Ability to link to other datasets:

- Metropolitan Atlanta Congenital Defects Program (MACDP)
- Georgia birth certificates (includes infant death file)
- Georgia death file (death certificates)
- Census track data (1990 & 2000)
- Other datasets for special studies (e.g. pediatric genetics clinics)



# Mental Retardation and Metabolic Disorders Metropolitan Atlanta, 1991-1994

Metabolic Disorder	Annual Rate per 100, 000 live births	# Expected Children with MR	# Observed Children with MR
Phenylketonuria	6.2	23	0
Homocystinuria	0.3	1	0
<b>Maple syrup urine disease</b>	<b>0.8</b>	<b>3</b>	<b>1</b>
Tyrosinemia		0	0
Hypothyroidism	20.3	74	0
<b>Classic galactosemia</b>	<b>12.8</b>	<b>47</b>	<b>1</b>



# Concerns Over Possible Rising Rates of Autism...

**Three US studies from 1980's and early 1990's**

- **Autistic disorder: 0.3-0.4 per 1,000**

**Estimates from outside the US in the 1990's**

- **Autistic disorder: 1 per 1,000**
- **Autism spectrum: 4-5 per 1,000**

**1998 CDC study in one US community, Brick, NJ**

- **Autistic disorder: 4 per 1,000**
- **Autism spectrum: 6.7 per 1,000**

**Significant increases in autism reported by service providers  
(California DDS and DOE data)**



## **MADDSP 1996 Autism Pilot**

- Is it possible to obtain prevalence estimates of autism in a defined population by reviewing and coding children's education and clinical records for behavioral descriptors?**



## Autism Case Definition

- A child is included as a confirmed autism case if he or she displays behaviors (as described in evaluation reports by a qualified professional) consistent with the *DSM-IV* diagnostic criteria for Autistic Disorder, PDD-NOS, or Asperger's Disorder as scored by an expert reviewer.



# MADDSP Approach for ASDs

## Identify potential cases at different data sources

- Schools – psychoeducational evaluations and select special education records
- Clinical sources - ICD codes, DSM-IV codes

## Screen source files of potential cases for autism indicators (“triggers”)

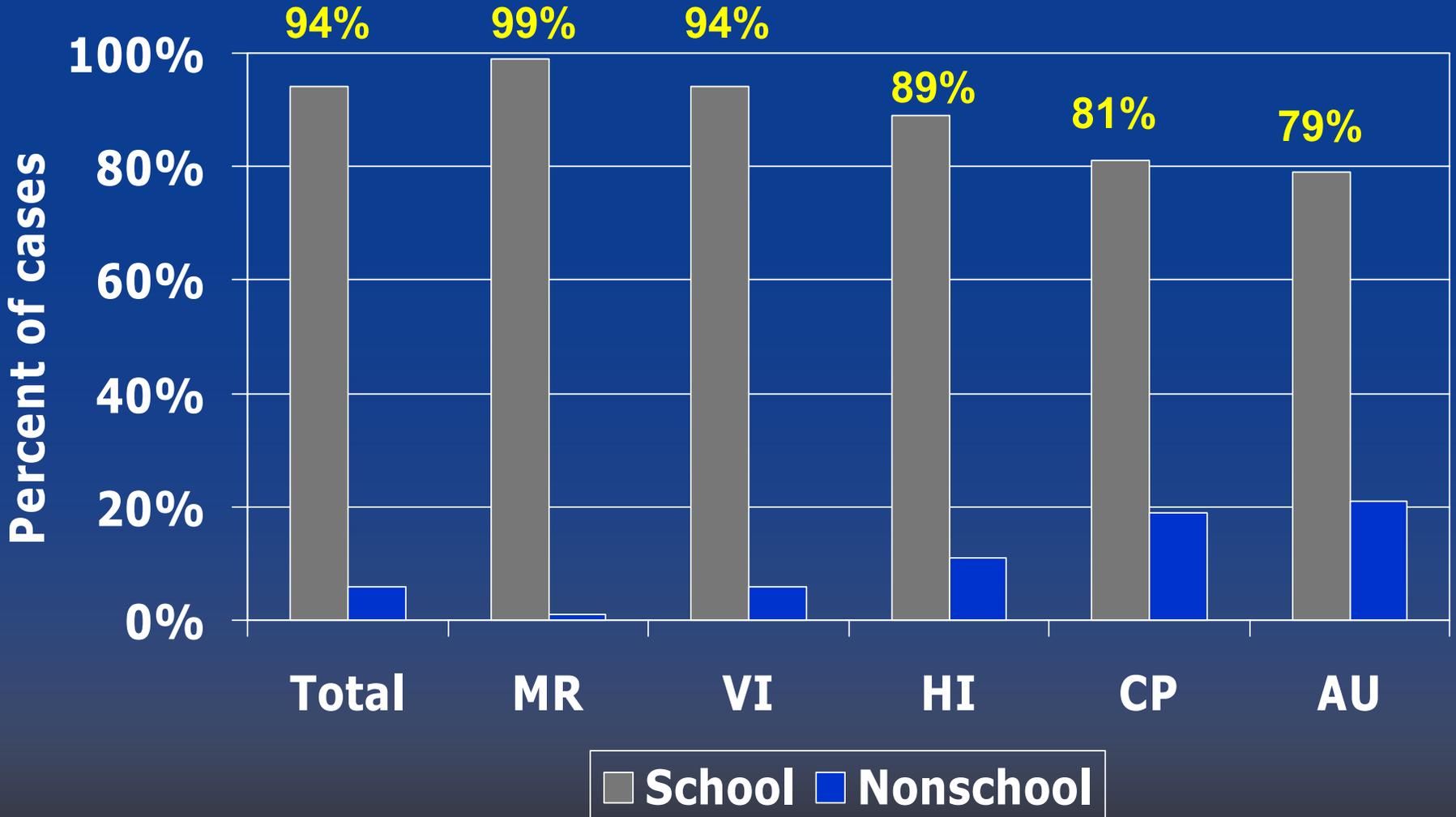
## Abstract potential cases identified

## Clinician review and behavioral coding of abstracted children’s records to determine case status

- Autism Case (Autistic Disorder or ASD-NOS)
- Suspected Case
- Not a Case

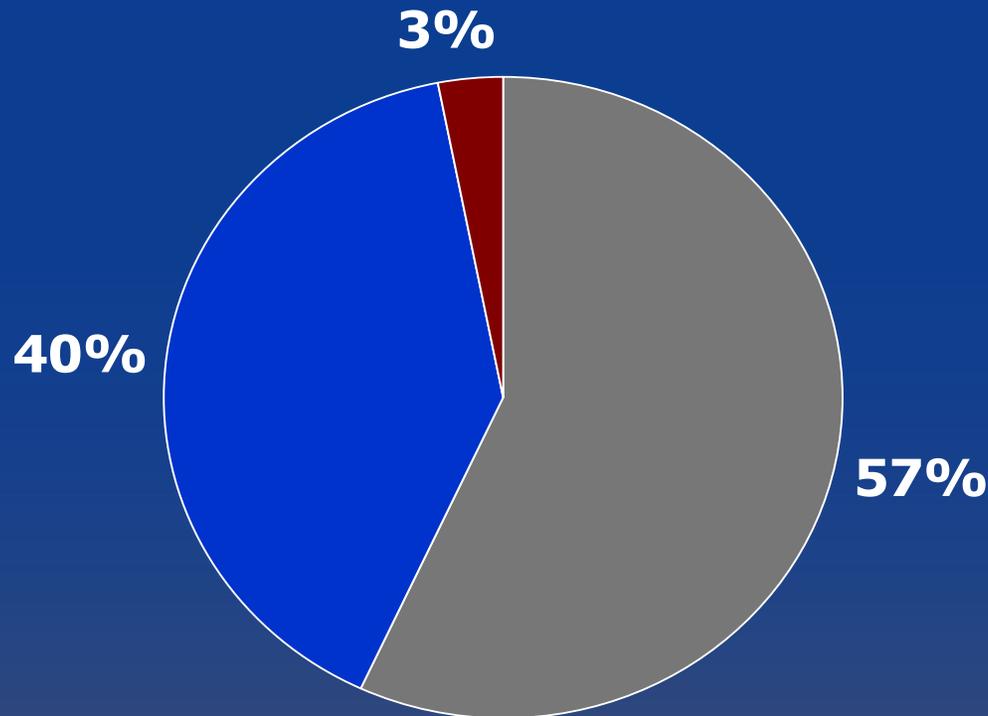


# MADDSP 1996: Initial Abstraction Sources





# MADDSP: Autism Cases (Age 3-10 yrs) Abstraction Sources



**40% would have been missed if there was no abstraction at school sources**





# MADDSP Summary of Data Source Trends

## School Sources Only

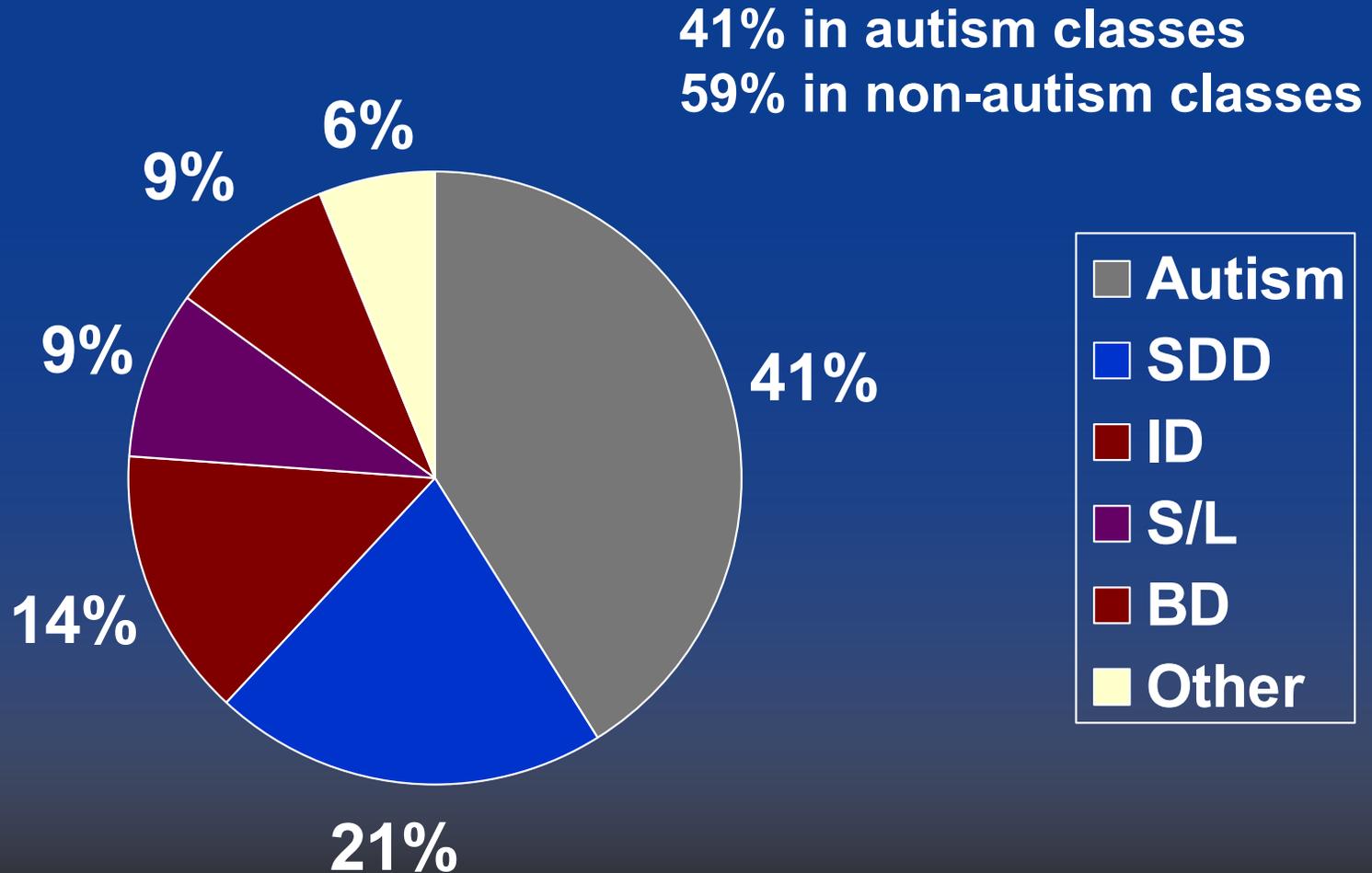
- 6-10 year olds
- Black children
- Mothers with  $<$  or  $=$  to 12 yrs education
- Mothers  $<$  20 years old
- Previous Diagnosis of Suspected, non-ASD, or not stated

## Nonschool Sources Only

- 3-5 years old
- White children
- Mothers with 13+ years of education
- Mothers 30+ years old
- Previous ASD Diagnosis



# MADDSP: ASD Cases (3-10 year olds) Primary Exceptionality





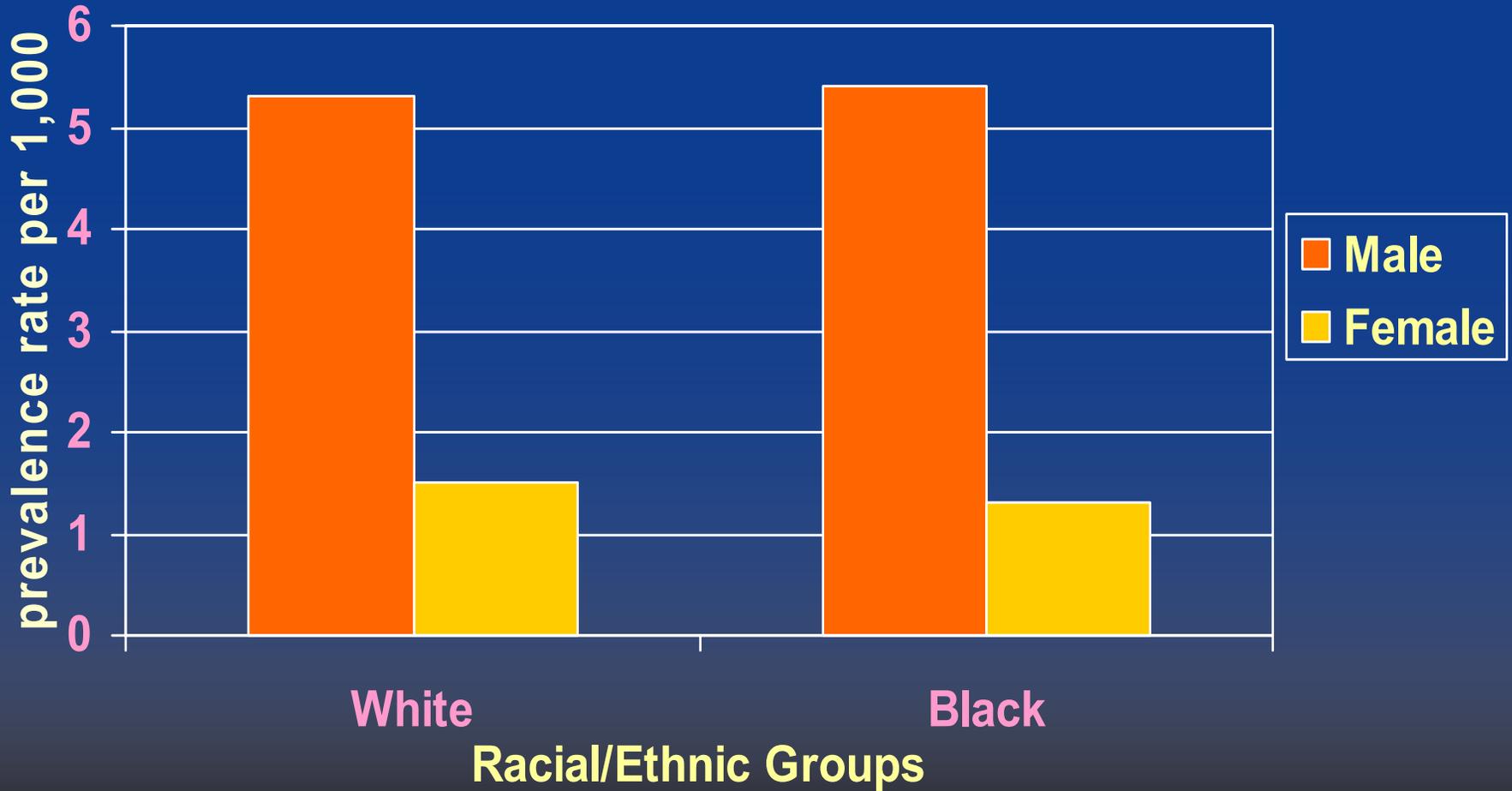
## Results: Prevalence of ASD by Age Groups per 1,000

<u>Age group</u>	<u>N</u>	<u>Prevalence rate per 1,000</u>
3-10 year olds	987	3.4 (3.2-3.6)
3-5 year olds	346	3.1 (2.7-3.4)
6-10 year olds	641	3.6 (3.3-3.9)

\* Denominator: 289,456 3-10 year old children in metropolitan Atlanta in 1996



# Prevalence by Race and Gender, 3-10 yr-olds





## Presence of Co-existing Impairment

	<u>N</u>	<u>%</u>
<u>Isolated ASD</u>	<u>376</u>	<u>38</u>
<u>ASD Plus Another Disability</u>	<u>611</u>	<u>62</u>
<b>Type of DD</b>		
◆ Mental Retardation	581	59
◆ Cerebral Palsy	49	5
◆ Hearing Loss	14	1
◆ Vision Impairment	12	1
◆ Epilepsy	76	8



## MADDSP is Unique

No other *population based* surveillance system for *multiple* developmental disabilities using data gathered on *individual children*



## Lessons from the MADDSP...

- **Schools are the primary source of information for children with developmental disabilities**
  - **Majority of children identified at schools**
  - **Schools provide unique sources of developmental status of children**
- **Case identification required at multiple public and private facilities to avoid under-ascertainment.**



# Strengths and Limitations of MADDSP Methodology

## Strengths

- Population–based estimates
- Very high ascertainment
- Ability to:
  - characterize developmental disabilities by type, severity and presence of co-existing conditions.
  - examine wide-range of characteristics of children with developmental disabilities.
  - link to other datasets to address additional hypotheses

## Limitations

- Timeliness
- Resource intensive





## **HELIX-Atlanta: Health and Environment Linked for Information Exchange**

- **Developmental Disabilities Team is participating in the development of HELIX-Atlanta**
- **MADDSP is one of the existing surveillance information systems in the 5-county Metropolitan Atlanta area proposed to participate in the network of integrated environmental monitoring and public health data systems.**



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